



King's Research Portal

DOI:

[10.1080/09699260.2015.1123441](https://doi.org/10.1080/09699260.2015.1123441)

Document Version

Publisher's PDF, also known as Version of record

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Turner, K., Tookman, A., Bristowe, K., & Maddocks, M. (2016). 'I am actually doing something to keep well. That feels really good': Experiences of exercise within hospice care. *Progress in Palliative Care*, 24(4), 204-212. <https://doi.org/10.1080/09699260.2015.1123441>

Citing this paper

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

General rights

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.



Progress in
Palliative
Care

Editor in Chief: Mollie Davis



Progress in Palliative Care

Science and the Art of Caring

ISSN: 0969-9260 (Print) 1743-291X (Online) Journal homepage: <http://www.tandfonline.com/loi/yppc20>

'I am actually doing something to keep well. That feels really good': Experiences of exercise within hospice care

Karen Turner, Adrian Tookman, Katherine Bristowe & Matthew Maddocks

To cite this article: Karen Turner, Adrian Tookman, Katherine Bristowe & Matthew Maddocks (2016) 'I am actually doing something to keep well. That feels really good': Experiences of exercise within hospice care, *Progress in Palliative Care*, 24:4, 204-212, DOI: [10.1080/09699260.2015.1123441](https://doi.org/10.1080/09699260.2015.1123441)

To link to this article: <http://dx.doi.org/10.1080/09699260.2015.1123441>



© 2015 The Authors. Published by Informa UK Limited, trading as Taylor & Francis Group.



Published online: 18 Jan 2016.



Submit your article to this journal [↗](#)



Article views: 709



View related articles [↗](#)



View Crossmark data [↗](#)

‘I am actually doing something to keep well. That feels really good’: Experiences of exercise within hospice care

Karen Turner^{1,2}, Adrian Tookman², Katherine Bristowe³, Matthew Maddocks³

¹Royal Free London NHS Foundation Trust, London, UK, ²Marie Curie Hospice Hampstead, UK, ³King's College London, Cicely Saunders Institute, London, UK

Background: Patients with advanced cancer frequently experience functional impairment and reduced quality of life. Therapeutic exercise can provide benefit and be made accessible through the use of tailored programmes. Most studies examining exercise programmes for people with advanced cancer have used quantitative outcome measures and focussed on objective physical function, therefore offer a limited perspective on the experience of exercise participation.

Methods: This qualitative study explored patients' experiences of an exercise programme within a palliative care setting. The interviews focussed on the perceived impact on all aspects of quality of life.

Results: Nine people with advanced cancer, attending a hospice-based exercise programme, completed a one-to-one interview with a senior physiotherapist to explore the physical, emotional, and social impacts of their participation. Interviews were audiotaped, transcribed verbatim and analysed using interpretive phenomenological analysis. Patients reported an awareness of the positive physical, psychological, and social consequences of exercising. Their experiences reflected on all dimensions of quality of life, the impact of others and the sense of meaning gained through participation in exercise.

Conclusion: Our findings highlight that exercise in palliative care should not be viewed solely a physical intervention, but one that has potential to enhance many aspects of patients' quality of life.

Keywords: Advanced cancer, Exercise, Palliative care, Phenomenology, Quality of life, Rehabilitation

Introduction

People with advanced cancer encounter complex problems due the disease and its treatment, which impact adversely on their daily lives.¹ In particular, cancer causes functional impairment including a reduced exercise capacity, physical inactivity, and a loss of ability to complete basic and extended activities of daily living.² Functional deficits often compound patient suffering through emotional and social distress, physical dependency and a lowering of self-efficacy, all contributing to a poor quality of life.^{3,4} This is especially evident in patients with progressive disease, who face a high symptom burden and often experience a rapid loss of function.

Strategies to improve, maintain, or slow down the decline in, physical function may impact positively on quality of life.⁵ Strong evidence supports the use of exercise in people with early stage cancer as a

safe, well-tolerated intervention that can reduce symptoms and improve physical and psychological functioning, translating into improvements in overall quality of life.⁶ The role of exercise for people with progressive, incurable cancer has received relatively little attention. Studies have shown that physical benefits can be achieved in selected patients,⁷ but the focus has been on objective markers of physical performance.⁵ As such, the benefits of exercise on broader psychological or existential aspects of function may not have been fully realized, and exercise is not widely regarded as an intervention to improve quality of life. In the context of advanced progressive cancer, relief of suffering may be an equally important focus as any objective functional gain.

When studying the effects of exercise on quality of life, generic health status questionnaires such as the EQ-5DTM fail to capture the range and depth of patients' emotions, behaviours, and reasoning. In patients receiving palliative care, objective quality of life instruments may also be unresponsive due to

Correspondence to: Karen Turner, Marie Curie Hospice Hampstead, 11 Lyndhurst Gardens, London NW3 5NS, UK.
Email: karen.turner@mariecurie.org.uk

floor effects. Patients' own perceptions will provide rich and meaningful data about their experience of exercise. To date, only two studies have investigated experiences of patients with advanced cancer undertaking exercise. The first highlighted the secure and caring group dynamic that an exercise class offered, which enhanced patients' coping.⁸ In the second, patients reflected on the structure that physical activity gave everyday life.⁹ We report qualitative findings from interviews with patients who participated in an individually tailored exercise programme, offered within a hospice setting. Our aims were to gain insight into the experiences of patients living with cancer taking part in exercise classes, the meaning they attached to participation, and to understand how they perceived participation to have affected their lives.

Methods

We adopted a Heideggerian phenomenological approach with the goal of increasing understanding of the meaning of human experiences through an interpretive methodology.¹⁰ Phenomenology emphasizes understanding more than description to allow a greater depth of insight into the patient's world as they experience it and the meanings they attach to those experiences. The Heideggerian tradition is known as hermeneutic or interpretive; the goal being to increase understanding of the meaning of human experiences or practices.¹⁰ Heidegger¹¹ describes 'being-in-the-world' as we are constantly adapting to situations and the phrase refers to the way human beings exist, act and are involved in the world. He advocates the utilization of hermeneutics as a method founded on the ontological view that lived experience is an interpretive process.

Setting

This study was conducted in the Marie Curie Hospice Day Therapy Unit in Hampstead, London. The hospice adopts a multi-disciplinary approach to rehabilitation and the gym, where exercise takes place, is staffed by physiotherapists, occupational therapists and volunteers. About 50 patients attend the gym each week. Each patient follows an individually tailored exercise programme, devised taking into consideration their personal aims, ability and relevant contraindications or precautions. Exercise stations include a static bike, treadmill, a MOTomed® and various fixed resistance machines to improve upper limb and lower limb strength. The length of session depends on the patients' ability and fitness levels and can vary between 10 minutes and 1.5 hour. The majority of users attend once or twice a week and are encouraged to exercise at home also. There is no cap on programme length, but patients are given

information about available local gyms as appropriate once they are confident with their exercises if this is a more convenient option for them. Patients do not have to enrol in a particular programme but follow a plan specifically designed for their needs.

Sampling

Information about the study was displayed on a poster in the gym. Interested patients were offered a participant information sheet and included if they had attended the gym on at least three occasions, were able to verbally convey their thoughts and views on its impact, and had cancer that could not be cured. It was felt that patients who had attended only once or twice may not have had sufficient experience to comment in depth on its effects. In line with our phenomenological approach and focus on the quality of the study phenomenon, a minimum of six participants were sought. Recruitment continued throughout the time period covered by ethical approval. All patients gave written informed consent in accordance with the principles of Good Clinical Practice and the Declaration of Helsinki. The study was approved by the East London and the City Research Ethics Committee (Ref. 09/H0704/51).

Interviews

One-to-one interview is considered the main method of data collection in phenomenological research.¹² Interviews were scheduled at the patient's convenience while they were attending the Day Therapy Unit and were conducted in a comfortable room without any interference. The interviewer (KT) was a senior physiotherapist with extensive clinical experience and a clinical relationship with study participants. As this study represented her first qualitative research, interview techniques were piloted and supervision was offered by an experienced independent academic tutor. Each semi-structured interview began with a verbal description of the purpose of the study; to understand patients' experience and perceptions. The research question was used as the first interview question; 'Can you explain to me whether participating in the gym sessions here has, in any way, affected your quality of life?' It was felt that the initial question should encompass the main theme of the interview and allow patients to explore and verbalize their experiences freely. After the patient had answered this initial question, the interviewer invited patients to clarify or expand on what had been said, using ideas that had emerged from the dialogue. The interviewer asked follow-up questions and on occasions, used appropriate standardized prompts to explore the physical, emotional and social impacts (see Supplementary material).

Data handling and analysis

Interviews were audio recorded, transcribed *verbatim*, and participants' were allocated a pseudonym. Data analysis was carried out manually (KT) following guidelines for interpretive phenomenological analysis.¹³ Each printed transcript was read and initial thoughts, comments and points of potential significance were recorded. Each transcript was then re-read several times. Margins were used to make notes on anything that seemed significant or of interest, to identify convergences and contradictions, and to transform initial notes and ideas into more specific themes or phrases. This involved further reading of the texts to reduce data by establishing connections between preliminary themes and clustering them appropriately. Major-themes, themes and sub-themes were described and verified by an independent academic tutor. Major-themes were common to all participants, while themes and sub-themes were created from fewer patient extracts.

Results

Participants

Ten patients consented to be interviewed, however, one participant died before the interview could take place. Nine interviews were completed. Table 1 below provides information about study participants. Participants' ages ranged from 55 to 82; six were married, two single and one widowed; all had a cancer diagnosis (lymphoma, breast, ovarian, prostate, myeloma, pancreatic, brain, and lung); three had attending the gym 10 or less times, three had attended 11–20 times, and three greater than 20 times (highest attendance over 100 times).

Findings

Three major-themes emerged from the data: consequences of attending; impact of others; and sense of

meaning. Table 2 presents the emergent major-themes, themes, and sub-themes.

Major theme 1: consequences of attending

The major theme of consequences of attending the gym, as described by participants, could be broadly separated into two emergent themes: physical consequences and psychological impact.

Theme: physical consequences

All participants reported physical impacts of attending the gym. They described physical problems associated with living with advanced cancer and/or the treatment they had received. These included: loss of muscle power and bulk; generalized weakness and tiredness; problems with balance; movement difficulties; and pain. Participants also shared difficulties engaging in previous activities such as walking, dancing, and gardening.

Sub-theme: strength and fitness

Improvements in physical status, as a result of attending the gym, were described by all participants. These included increases in strength, fitness, movement, and function.

...it's strengthened the legs and the upper body. Very specifically it's a geared programme designed for my particular needs to get the strength back in the legs to get some balance back.

Andrew, 74, living with metastatic prostate cancer

The individually designed nature of the programme was recognized as a particular positive for participants.

Sub-theme: movement and function

Impacts of exercise upon movement and function in their day-to-day life were also shared by participants. The functional benefits of exercise experienced by participants included positive impacts upon their mobility, walking, movement, and flexibility.

They are getting me mobile and much better especially like at home, because I have stairs to climb. I haven't got a lift where I live...and it's helped me no end getting up the stairs...It's been very very beneficial to me, really wonderful.

Rachel, age 82, living with metastatic ovarian cancer

Sub-theme: physical cost of not attending

Patients also appeared to be very aware of the physical impact that not attending would have on them, expressing that their balance; muscle bulk, movement and

Table 1 Study participant characteristics

Pseudonym	Age	Relationship status	Cancer diagnosis	Number of previous gym attendees
Susan	77	Married	Advanced lymphoma	8
Jenny	57	Widow	Metastatic breast	5
Rachel	82	Single	Metastatic ovarian	10
Jacob	62	Married	Metastatic prostate	32
Catherine	55	Long term partner	Multiple myeloma	12
Lorraine	80	Single	Ovarian and pancreatic	44
Mary	77	Married	Brain tumour	100+
Andrew	74	Married	Metastatic prostate	13
Diana	55	Married	Metastatic lung	20

Table 2 Themes that emerged from qualitative interviews regarding patients' experience of exercise within hospice care

Major-themes	Themes	Sub-themes
Consequences of attending	Physical consequences	Strength and fitness Movement and function Physical cost of not attending
	Psychological impact	Positive emotional effects Positive outlook on self and life Sense of achievement
Impact of others	Influence of other patients	Encouragement/camaraderie Comparison with others Social aspect Loss
	Professional involvement	Support Expectations Importance
Sense of meaning	Attitude towards exercise in the gym	Toil Positive involvement in own health Reclaiming control
	Active in own wellbeing	Importance of choice Prolonging independence Confidence and hope Declining despite exercise Not giving up
	Facing the future	

function would be in a poorer state had they not been exercising.

I am sure if I had not gone, all my body would have seized up, my back would have seized up, my muscles as well, the whole thing would have been a disaster. So it has helped me, helped my quality of life in terms of the way I feel. I'm positive about that.

Jacob, aged 62, living with metastatic prostate cancer

The positive impact upon their ability to continue day-to-day activities, and upon their quality of life, was recognized.

Theme: psychological impact

The psychological impacts of exercising, and attending the gym, were evident from the interviews. Whilst some participants described the depression, frustration, anger and powerlessness associated with living with advanced cancer and disability, exercising in the gym provided them with a source of positivity and focus.

Sub-theme: positive emotional effects

Patients' described the soothing emotional influence of attending the gym, which they considered relieved their stress, and promoted calm and relaxation. Participants experienced the uplifting effects of exercising in the gym, including: feelings more focussed, cheerful, energized, boosted, and having an improved mood.

I'm glad we had the conversation. It has made me think about what the gym, I was thinking about it before, meant to me. I can't see it like

huge physical, but it is the mental and emotional benefits of the gym

Diana, aged 55, living with metastatic lung cancer

Sub-theme: positive outlook on life and self

However, these positive emotional impacts were also extended to life outside of the gym. Attending the gym not only affected participants' mood, but also the way they perceived themselves, their lives and their situation.

It would be easy to think of myself as an invalid, em because I can't do what I used to be able to do, but it slows down the slide into invalidity mentally if you see what I mean. Less likely to think of myself as an invalid...Yeah... it has had a positive effect on the way I view myself.

Jenny, aged 57, living with metastatic breast cancer

Sub-theme: sense of achievement

For some participants attendance at the gym was also associated with a sense of achievement relating to: actually getting to the gym, carrying out the exercises, and, in one case, having managed to do more than the week before. The sense of achievement was present, regardless of duration or intensity of exercise.

And having done it (the exercise), I feel, I feel a sense of achievement as though I have a small halo around my head.

Mary, aged 77, living with brain tumour

Major theme 2: impact of others

The second major theme emerging from the data was impact of others. Patients in the gym are not exercising alone and all patients mentioned the effect that others have on their experience, both other patients and the impact of staff.

Theme: influence of other patients

The influence of other patients was mentioned by all but one of the interviewees. Six appeared to have an overwhelmingly positive experience of exercising in a group setting:

Sub-theme: encouragement/camaraderie

There are many references to participants being encouraged by other patients in the gym, and the sense of camaraderie amongst them.

you're sort of encouraging them and they are probably encouraging you as well to get in there and do

Catherine, aged 55, living with multiple myeloma

Often participants also described that seeing others in a similar situation was heartening and encouraging.

everyone is in the same boat all trying to get your limbs to work and that's what I really, really like about it.

Jenny, aged 57, living with metastatic breast cancer

Sub-theme: positive comparison with others

However, sharing the gym space also enabled participants to compare themselves to others who were not as physically fit or able as themselves. They described admiration for others who are in a worse physical state and still exercising.

it gives you the incentive...to do your own exercise, I think you know, when you see people who can't move as, as well as yourself, and they are actually sitting there on the bike, or you know, and giving it a go. You think...if they can do it, give it a go and you can do it well. I think it encourages you, you know it gives you the incentive to do your own exercise

Catherine, aged 55, living with multiple myeloma

Sub-theme: social interaction

The gym also served a social function, offering an alternative environment where social interactions took place, promoting a sense of belonging and feeling of engagement with others. Patients commented on the community environment that the gym creates.

I live alone and it gets you out, gets one out, and it gets you meeting people, which is a good thing.

Jenny, aged 57, living with metastatic breast cancer

Sub-theme: loss

However, a consequence of the social nature of the gym, and becoming closer to other patients, was the sense of loss when they were no longer able to attend, or died. Only two participants mentioned loss, however through the researcher's years of experience in the gym, the deep impact of the loss of fellow patients has been observed, as described below.

And the sad bits of it when I miss people who are not there and they've died.

Diana, aged 55, living with metastatic lung cancer

Theme: professional involvement

Participants' experiences of the gym were also shaped by the involvement of the professional staff, as well as the professionals' expectations. Seven participants commented on the experience of having professional involvement in the gym.

Sub-themes: professional support

Participants acknowledged the level of support and attention they received from professionals, which contributed to a sense of belonging, as described below.

You can belong here which is wonderful, and I do appreciate it and it does makes me feel very grateful at times and also the support is phenomenal, you know.

Diana, aged 55, living with metastatic lung cancer

Sub-theme: expectations

However, they were also mindful of the expectations of staff. Staff managed to encourage patients, whilst also ensuring they did not have a sense of failure if they were unable to complete a particular exercise. Three participants talked about the attitude of the physiotherapists towards the amount of exercise they are able to do.

So there is an expectation that you will do your best to get whatever is able to be got out of you, that you are going to do it and...whatever you achieve is an achievement and that is a psychological boost as well as a physical boost.

Mary, aged 77, living with brain tumour

This encouragement without expectations was pivotal for participants in order to maintain positivity when attending the gym.

Major theme 3: sense of meaning

The third major theme emerging from the data related to participants' feelings towards the gym, and the meaning they associated with it. This theme encompassed attitudes towards exercise in the gym, playing an active role in optimizing their wellbeing, and facing the future.

Theme: attitudes towards exercise in the gym

Participants described their attitudes towards the gym, both the importance of attendance, but also the toil, and crucial work, it involved.

Sub-theme: importance

The value of attending the gym setting was recognized by participants, as was its importance as part of the treatment process, compared to other therapies.

I think it's almost essential (to have a gym in a hospice). Because I don't feel the patients are getting 100% treatment if they don't have that...I think it's vital to have machines. I mean I've seen what happens to the other patients here and they certainly seem to be better for it.

Lorraine, aged 80, living with ovarian and pancreatic cancer

Sub-theme: toil

However, participants also described their dedication to the programme, akin to a job or work, and the determination required to continue the programme alongside their illness.

I think we work, people in there. You know in an ordinary gym you kind of see people preening and looking absolutely beautiful, watch me, watch me, they are so good at things, beautiful to look at. Yes it's different. We are here to do some work, it's more that keeping fit. I think sometimes you have to be quite determined to do this gym, when you are not well

Diana, aged 55, living with metastatic lung cancer

The ethos in the hospice gym related to more than just keeping fit or enjoying the experience, as would be the case in a more generic gym setting, but also to the work that needed to be done to optimize their health.

Theme: active in own wellbeing

This sense of working to promote their own wellbeing was recognized by seven of the participants. They were not passive recipients of care, but physically doing

something to help themselves, retaining a degree of choice and control.

Sub-theme: positive involvement in own health

Participants reported feeling good about doing something for themselves, and the positive emotional impact associated with this active involvement in their own healthcare.

it makes me feel physically better but it makes psychologically better too. I feel that I have done something for my own benefit

Mary, aged 77, living with brain tumour

Sub-theme: reclaiming control

However, they also described how participation in the gym programme helped to redress the balance of control. Where cancer leaves the individual feeling powerless, participation in the gym programme empowered them to reclaim some control.

I am actually doing something to keep well. That feels really good in the situation where cancer makes you feel very powerless because it's out of your control. Here is something albeit small but to me know it's big, it is in my control, keeping this aspect of keeping well. I can get to the gym, I can walk, I can make my heart rate increase, I can strengthen my limbs as much as I'm able. That control is very good for someone who feels they have so little control

Diana, aged 55, living with metastatic lung cancer

This is further demonstrated by the participant's repeated use of the first person pronoun ('I'), demonstrating ownership and agency in this role.

Sub-theme: importance of choice

Relating also to the importance of control, participants valued having choices to make. This patient describes how deciding to come to the gym gives her a sense that she is still in a position where she has choices to make.

one of the things that happens as you get ill is that your choices get swept away inevitably I'll end up with no choices at all but having things to choose today. I can choose not to come but I choose to come and I'm in control then.

Jenny, aged 57, living with metastatic breast cancer

Theme: facing the future

All participants interviewed had incurable cancer, and it was anticipated that their health would continue to deteriorate as their disease progressed. Some of the

participants interviewed alluded to the future and the extent of the impact participation in the gym programme had on their outlook.

Sub-theme: prolonging independence

Three patients spoke about how exercising played a role in maintaining as great a level of function as possible, for as long as possible.

I'm sure that the visits to the gym are actually helping, it's postponing the day that I will lose mobility. I'm not saying that it's a major factor but I'm sure it does help.

Jacob, aged 62, living with metastatic prostate cancer

The exercise programme was viewed as a tool or weapon to push back against the progressing illness.

Sub-theme: confidence and hope

The programme was also described in relation to the confidence and hope it instilled in participants, reminding them of what they are able to achieve.

And I think the exercise does help me to maintain what I've got, you know, level of fitness and I think it reminds me that I can do things

Jenny, aged 57, living with metastatic breast cancer

Sub-theme: declining despite exercise

However, participants also recognized their deterioration despite exercising. When their health was fluctuating, it impacted upon how much exercise they are able to do, compared to previous sessions.

doesn't feel so good. Being able to do less. I may not be able to do so much today, I've got some work to do in learning to accept that you go up and then down and not just up

Jenny, aged 57, living with metastatic breast cancer

However, this did not necessarily deter participants from attending the gym, as described by one participant.

I'm pleased to be able to do it. I'm pleased to be able to do that, even if it's less than the month before and even if the month before is less than month before and even if it's dwindling.

Jacob, aged 62, living with metastatic prostate cancer

Sub-theme: not giving up

Lastly, participants described the pivotal role of the exercise programme, and attending the gym, in maintain hope, and not giving up. Despite their advancing

disease they had not resigned themselves to the fact that nothing can be done, and chose to spend their time trying to maximize their physical potential.

It doesn't do to just give up; I know that, I've just got to fight it.

Susan, age 77, living with advanced lymphoma

As well as not giving up, participants described exercise as a proactive way of combating their illness, and a means to maintain their quality of life. Not giving up was often associated with battle metaphors.

Obviously there are other forces at work in my body...but the gym is actually a weapon I have against these forces of mobility and what's working against that and which will eventually win, but nonetheless I can push it forward in time. So in that sense, it helps me keep a certain quality of life.

Jacob, aged 62, living with metastatic prostate cancer

Discussion

We interviewed patients with advanced cancer participating in a hospice-based exercise programme within palliative care. Patients shared experiences and related exercise to perceived impacts upon their physical condition, psychological state and cognitive functioning, suggesting that participation had a positive effect on quality of life. Major-themes from the interviews were the consequences of attending, both physical and psychological, the impact of others, professional and peers, and the sense of meaning gained through participation. These themes link to known constituents and moderators of quality of life in advanced cancer, including one's health state, relationships, and future outlook.¹⁴

These findings of this qualitative study augment and extend those reported in previous quantitative studies. Participants' experiences regarding physical improvements are in line with improvements in objective physical function found in exercise trials in patients with advanced disease in hospital⁵ and hospice outpatient settings.¹⁵ Participants were able to find and convey meaningful benefit from improvements in strength, for example, into an ability to climb the stairs in their home with more ease. According to Cohen and Leis,¹⁴ physical functioning is one of the most important determinants of quality of life. Indeed, patients with advanced disease often report distress from the loss of ability to manage daily activities independently.⁴ Patients also described psychological benefits of participation in exercise, and attending the gym impacted positively upon their outlook on both their life and themselves. The sense of achievement

described by patients in this study also echoes previous literature.¹⁶ Our findings lend further support to the notion that exercise can provide benefits beyond physical outcomes, and have a positive impact on quality of life through an improvement in psychological status.

The impact of others in the gym, both staff and patients, had an overall positive effect on the experience of exercise. Patients reported that they felt supported by the staff in the gym. Cohen and Leis¹⁴ highlighted quality of care as an important determinant of perceived improvements in quality of life and here the staff role was central to a positive patient experience of exercise. The gym in the hospice is staffed by professionals and volunteers. Both groups contributed to the social environment described, which highlights an important novel role for hospice volunteers. The social dimension of exercising with other patients has been reported in previous studies.^{17,18} Participants spoke about feelings of belonging, membership and a shared experience which emerged from the group setting. One downside of exercising with others in this particular setting was the loss participants' felt when someone died, or was no longer able to attend due to deteriorating health. This theme of shared loss has not to our knowledge been reported in the rehabilitative literature, but is recognized in others with chronic disease, particularly in relation to facing one's own mortality.¹⁹

Interesting findings also came under the theme 'sense of meaning'. At times patients viewed exercise in the gym as a 'job', and their attitude was one of preparedness for the serious task ahead. This was further underpinned by the sense of agency and responsibility patients described in their approach to their time in the gym. Participants expressed strong feelings relating to being actively involved in their own wellbeing. The importance of a sense of reclaimed control has been reported elsewhere²⁰ as has the negative impact on quality of life when patients perceive a lack of control over their own life.¹⁴ Those attending the gym enjoyed a sense of control when able to attend, as well as when able to choose what type of exercises to do, and what order to do them in whilst in. Whilst this flexibility may compromise the potential for physical benefit and be discouraged in an intensive training setting, it appeared to foster a feeling of ownership which may encourage regular attendance.²¹

When considering the future, patients mentioned the importance of prolonging independence and one specifically spoke about delaying dependence on others for as long as possible. Participants talked about how the gym gave them confidence and hope that there was something that could be done to improve their situation. Some patients used battle metaphors and terms such as 'fight' and 'weapon' when talking about the interplay between their illness and

the exercise classes. Patients place great value and importance in attending dedicated spaces for exercise, but this resource is not commonplace and many patients with advanced cancer are not able to access similar services. Patients receiving palliative care often have difficulty accessing mainstream gym facilities, and there are calls to improve provision²² and staffing²³ of rehabilitation services within the hospice sector.

In early stage or curable cancer, patients often and rightly perceive that their physical status will improve with exercise. In contrast, many patients within this setting were unable to improve physically due to the constraints and impairments of their disease, as well as its progressive nature. The fact that patients continued to exercise, often in the face of deterioration, suggests that physical improvements, in and of themselves, are not the only reason to exercise. Many patients clearly reported overall benefit, even though gains were not reflected in their physical performance. The concept of 'declining despite exercise' has not received recognition in previous literature but is important for palliative rehabilitation to acknowledge and understand. Additional work to better understand this area would be valuable. Further areas for future research could include exploration of the existential benefits of exercise, e.g. on spirituality and feeling at peace, as well as acknowledging functional maintenance as a successful outcome in the context of advancing illness.

Limitations

There are limitations to the study. One researcher, who was relatively inexperienced and involved in the clinical care of study participants, conducted interviews and analysed transcripts. It is possible that her involvement in participants' clinical care may be impacted upon the conduct of the interviews. However, to mitigate against this, interview techniques were piloted, followed a stringent methodology, and themes were checked and verified independently by the research supervisor. In addition, the gym does not function independently but is part of a large Day Therapy Unit. The interview topics were constructed to focus on this aspect of care, though we acknowledge the possible impact of other services. In some respects, it is incongruous to look at participation in exercise at the gym without recognizing its setting with a palliative care unit.

Conclusion

This study sought to understand the experience of exercise as part of a group in a hospice gym setting, and perceived effects on quality of life in people with advanced cancer. Rehabilitation in cancer care has tended to focus on physical function using objective outcomes. Our findings highlight that exercise has

broad effects on quality of life in this setting. New insights into the meanings and values attributed to exercising have emerged, extending beyond physical dimensions of quality of life. Positive experiences of gym attendance arose from perceived gains in psychological health, the impact of others, and being actively involved in their own wellbeing.

Disclaimer statements

Contributors K.T. is the overall guarantor of this manuscript and takes responsibility for the content, including the data and analysis. The original study conception was by K.T. and A.T. K.T. and A.T. contributed to data acquisition. K.T., K.B., and M.M. undertook analysis of and interpreted data. All authors critically revised the manuscript and approved the submitted version.

Funding Karen Turner and Adrian Tookmans' hospice posts are supported by Marie Curie. M.M. is supported by a National Institute for Health Research (NIHR) Clinical Trials Fellowship. The views expressed in this publication are those of the authors and not necessarily those of the NHS, the NIHR nor the Department of Health.

Conflicts of interest There are no conflicts of interest to declare.

Ethics approval Thames Valley University, Faculty of Health and Human Sciences. FREC reference number: FREC28/08-09, IRAS reference number: 18261/38306/1/979. East London and the City REC Alpha, 2nd Floor, Burdette House, Mile End Hospital, London. REC reference number: 09/H0704/51. Research and Development Department, Royal Free Hampstead NHS Trust, Pond Street, London NW3 2QG. Research and Development ID: 7861.

References

- 1 Fialka-Moser V, Crevenna R, Korpan M, Quittan M. Cancer rehabilitation: particularly with aspects on physical impairments. *J Rehab Med* 2003;35:153–62.
- 2 Maddocks M, Murton AJ, Wilcock A. Improving muscle mass and function in cachexia: non-drug approaches. *Curr Opin Support Palliat Care* 2011;5(4):361–64.
- 3 Bjordal K, Freng A, Thorvik J, Kaasa S. Patient self-reported and clinician-rated quality of life in head and neck cancer

- patients: a cross-sectional study. *Eur J Cancer Part B: Oral Oncol* 1995;31(4):235–41.
- 4 Eva G, Wee B. Rehabilitation in end-of-life management. *Curr Opin Support Palliat Care* 2010;4(3):158–62.
- 5 Salakari MR, Surakka T, Nurminen R, Pytkäinen L. Effects of rehabilitation among patients with advanced cancer: a systematic review. *Acta Oncol* 2015;54(5):618–28.
- 6 Jones LW, Alfano CM. Exercise-oncology research: past, present, and future. *Acta Oncol* 2013;52(2):195–215.
- 7 Oldervoll LM, Loge JH, Lydersen S, Paltiel H, Asp MB, Nygaard UV, et al. Physical exercise for cancer patients with advanced disease: a randomized controlled trial. *Oncologist* 2011;16(11):1649–57.
- 8 Paltiel H, Solvoll E, Loge JH, Kaasa S, Oldervoll L. "The healthy me appears": palliative cancer patients' experiences of participation in a physical group exercise program. *Palliat Support Care* 2009;7:459–67.
- 9 Gulde I, Oldervoll LM, Martin C. Palliative cancer patients' experience of physical activity. *J Palliat Care* 2011;27(4):296–302.
- 10 Cohen MZ, Omery A. Schools of phenomenology: implications for nursing research. In: Morse JM, (ed.) *Critical issues in qualitative methods*. California: Sage; 1994. p. 136–56.
- 11 Heidegger M. *Being and time*. Oxford: Blackwell Publishers; 1962.
- 12 Wimpenny P, Gass J. Interviewing in phenomenology and grounded theory: is there a difference? *J Adv Nurs* 2000;31(6):1485–92.
- 13 Storey L. Doing interpretive phenomenological analysis. In: Lyons E, Coyle A, (eds.) *Analysis of qualitative data in psychology*. London: Sage; 2007. p. 51–64.
- 14 Cohen SR, Leis A. What determines the quality of life of terminally ill cancer patients from their own perspective? *J Palliat Care* 2002;18:48–58.
- 15 Talbot-Rice H, Malcolm L, Norman K, Jones A, Lee K, Preston G, et al. An evaluation of the St Christopher's Hospice rehabilitation gym circuits classes: patient uptake, outcomes, and feedback. *Prog Palliat Care* 2014;22(6):319–25.
- 16 Porock D, Kristjanson LJ, Tinnelly K, Duke T, Blight J. An exercise intervention for advanced cancer patients experiencing fatigue: a pilot study. *J Palliat Care* 2000;16:30–36.
- 17 Stevinson C, Fox KR. Feasibility of an exercise rehabilitation programme for cancer patients. *Eur J Cancer Care* 2006;15(4):386–96.
- 18 Midtgaard J, Rorth M, Stelter R, Adamsen L. The group matters: an explorative study of group cohesion and quality of life in cancer patients participating in physical exercise intervention during treatment. *Eur J Cancer Care* 2006;15:25–33.
- 19 Bristowe K, Horsley H, Shepherd K, Brown H, Carey I, Matthews B, et al. Thinking ahead – the need for early advance care planning for people on haemodialysis: a qualitative interview study. *Palliat Med* 2015;29(5):443–50.
- 20 Belchamber CA, Gousy MH. Rehabilitative care in a specialist palliative day care centre: a study of patients' perspectives. *Int J Therapy Rehab* 2004;11(9):425–34.
- 21 Maddocks M, Armstrong S, Wilcock A. Exercise as a supportive therapy in incurable cancer: exploring patient preferences. *Psychooncology* 2011;20(2):173–78.
- 22 Hopkins KF, Tookman AJ. Rehabilitation and specialist palliative care. *Intern J Palliat Nurs* 2000;6:123–30.
- 23 Wosahlo P, Maddocks M. Benchmarking the provision of palliative rehabilitation within the hospice setting. *Palliat Med* 2015;29(5):477–78.